

70 Farmington Avenue
Unit 4T
New London, CT 06320

Public Health Committee
Room 3000, Legislative Office Building
Hartford, CT 06106

February 26, 2007

Dear Public Health Committee Members:

Thank you for hearing my testimony today. I work on the issue of universal health care for Eastern Area Health Education Center. However, today I am here to tell you my personal story that illustrates the multitude of issues related to illness and access to care.

I had a long battle with a severe case of Neurological Lyme Disease, but I am fortunate because when I first became ill I was still in college and covered under my father's health insurance. I spent six weeks in the hospital having an extensive array of tests and procedures because I was severely ill but with a difficult case to diagnose. My symptoms included double vision, meningitis, neurological symptoms usually seen in severe spinal injuries, cognitive dysfunction, extreme weakness that left me bedridden, and severe gastro-intestinal issues. I am 5'11" and during my acute illness I weighed as little as 112 lbs.

After finally being diagnosed as having Lyme Disease, I required a long course of IV antibiotics. My story did not end there because unfortunately I had two relapses over the ten years afterwards and required follow up care. It was a long road through various treatments, some only dealing with specific symptoms when doctors were at a loss as to what to do next. I was told I had Chronic Fatigue Syndrome from the damage done to my body. Neurological Lyme Disease can be more complicated than the typical Lyme Disease tale of finding a rash and taking a course of antibiotics. I eventually found a doctor who knew how to treat my chronic Neurological Lyme Disease and was fortunate that she was able to see me as a patient because she accepted my current insurance. I know others who could have had their lives change for the better but did not have access to her care.

My insurance coverage during the past seventeen years illustrates the tenuous nature of access to care and the burden of its cost. Within a year of getting out of the hospital I no longer qualified for my father's insurance. Although I had gaps in coverage that made care difficult at times, I was fortunate because at the times I needed it most I was covered through various avenues. I was on Medicaid when I was disabled until I was able to get Medicare disability, which is a very difficult process when you have a complex illness that is not well understood. At one point I was able to get on my spouse's insurance and after divorce received COBRA.

Our current system creates a multitude of issues, rather than allowing the delivery of health care to be the focus. If I had still been on Medicaid when I had my second relapse, I would not have been able to get an appointment with the doctor who cured me. This is because, like many other providers, she cannot accept Medicaid due to the reimbursement rates. Even with insurance access is not guaranteed. The codes are tricky with a chronic illness and visits often only covered if the doctor happens to know how to negotiate the complex system.

As you can imagine, the cost of my original hospital stay and treatment was quite large, running in the tens of thousands of dollars. My family and I were not bankrupted simply because we had good insurance at the time.

If I did not currently have my COBRA I would go broke from the ongoing medications I take to keep the good health I have today. Some of the treatments and supplements that got me to where I am today are not covered by insurance. How ironic that the very cures that end my need for more costly medical care are not covered.

My COBRA will end soon and the religious congregation that is my primary employer is looking at several options. None of these are easy because it is a small workplace where other employees are covered under their spouse's plans and I do not qualify for an individual plan because of my pre-existing condition. My job with AHEC is contract work that does not offer coverage. I no longer am disabled but insurance is certainly a concern, although I am safe for the moment. My employer has the willingness and desire to provide insurance but, like many small businesses, feels the growing strain of meeting this moral obligation. In addition to the cost of coverage itself, there are an inordinate number of staff hours just to figure out what possible solutions are available.

I have my life back. I currently work two challenging jobs, am able to drive again, and have only slight remaining symptoms that do not hamper my activity level. But what if I did not have coverage during these difficulties? What if I did not have family and friends who helped with my care physically and financially? I have learned that access to health care is random in many ways. I should and do feel fortunate for my blessing of good health again. However, I should not have to feel lucky that I had access to the care I needed. If I feel lucky, then it means many others are not. I have heard their stories. I understand they struggle with health issues similar to mine but cannot access the care to overcome these obstacles.

We have great medical care available for many health issues people face today. We need to figure out how to make this care accessible for everyone. It is imperative morally and financially. When I look at my own experience and see the life situations of those around me, I recognize the importance of comprehensive reform that addresses the multi-faceted issues around health care.

I urge you as our leaders to act now because each day we leave this crisis unresolved is a day that hundreds of thousands of people are in danger of medical and financial disaster, while some are missing out on paths to wellness that exist but are unavailable to them. I

encourage you to use the Institute of Medicine's five principles as your guide in working through the complexities of comprehensive reform. Those five principles address the issues of affordability and accessibility. We must have the courage to address the big picture now. The daily consequences of not taking action far outweigh the difficulty of figuring out the solution to this crisis. Thank you so much for hearing our voices today and making universal health care a priority.

Sincerely,
Perry Montrose